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SUMMARY

This small exploratory study sought to understand how people with End Stage Kidney Disease (ESKD) experience the information environment and what information practices they employ in order to inform the decisions they make in relation to treatment and care. Using a constructivist methodology, in-depth interviews were conducted with five people who were receiving haemodialysis in two small satellite dialysis units located in regional and rural communities in New South Wales, Australia. Thematic analysis revealed two types of patients. The first type appears to adopt a received view of information, who do not question their condition; and passively accept information. In the other type, patients were found to be engaged; they actively identified their information needs and quickly learned what that they needed to ask and who to ask. Knowing the information practices of people with ESKD is useful for nephrology nurses when providing patient education.

Keywords: patient knowledge, information literacy, education

INTRODUCTION

Chronic kidney disease (CKD) is a complex and life-threatening health problem which requires people to invest considerable time and effort to understand and manage their significantly changed and impaired health status (Bonner & Douglas 2008). CKD is classified into 5 stages of severity, with stage 5 referring to end stage kidney disease (ESKD) where survival is dependent on renal replacement therapy. All people with CKD, regardless of stage, are required to adhere to modification of diet and the administration of numerous medications, and travel to attend frequent hospital appointments and/or dialysis treatment sessions (Bonner & Douglas 2008). CKD, its therapies and concomitant complications, pose significant difficulties for a satisfactory quality of life, due to complex physical, psychological and social changes (Mapes et al. 2004, Tallis 2005) and the impact on everyday activities (Bonner et al. 2009). One goal for people with CKD is to establish the foundations of positive self-care attitudes and practices. By gaining knowledge of their disease and how it is treated, the patient becomes an active participant in their management (Castner & Douglas 2005).

There is extensive literature examining the information needs of people with CKD (see for example Da Silva-Gane et al. 2002, Finklestein et al. 2008, Lewis et al. 2010, Yen et al., 2008). Ormandy (2008) in a systematic review identified information topic areas important for people with CKD. Pre-dialysis education is particularly important for people with CKD (Pagels et al. 2008, Yen et al. 2008) but when patients were asked to rate their level of knowledge after attending education sessions, about one-third reported limited or no understanding of their CKD (Finklestein et al. 2008). Recently Wright et al (2011) found that many topic areas important to supporting patients to perform self-care were in fact not well understood by patients with CKD.

Information practice is a relatively new area of enquiry in the information sciences and in nursing and, to-date, there has been little reported research in either of these fields (Tuominen et al. 2006). Information practice can be defined as a bundle of organized human activities that enable access to information that is socially constituted within a community of people who share similar narratives (Lloyd 2010). Information practices include seeking information from a variety of sources, the sharing of information, evaluating information, thinking critically about information and reflecting upon it. How a practice is shaped will be dependent on the context and the values people place on information. Focusing on information practice will enable researchers to examine the underlying relationship between information, knowledge and experience.

STUDY

The aim of this exploratory study was to understand how people with ESKD experience the information environment and what information practices they employ in order to inform the decisions they make in relation to treatment and care. Situated in the constructivist paradigm in which multiple, subjective realities are constructed (Polit & Tatano Beck 2010), this exploratory qualitative study was informed by both Habermas' communicative action and practice theory (Schatzki 2002). Habermas' theory of communicative action (1987) suggests that there are two dimension; a lifeworld as a place of communicative action and a system, a place for instrumental action. The lifeworld as a social space serves a number of functions - it provides the context for shared meaning and assumptions, for background knowledge and for shared reason. The concept of practice theory (Schatzki 2002) provides a framework for understanding how social life is constituted and transformed through practices that occur within a setting. Both of these perspectives provide a set of constructs that enable us to

understand how people develop their realities about renal disease and the information practices they use; that is, this research explores perspectives from a person's (real) lifeworld.

Consistent with exploratory qualitative research, the sample size for this study was small, appropriate and sufficient (Liamputtong & Serry 2010, Polit & Tatano Beck 2010); with an emphasis on eliciting deep responses. This research design does not require a homogenous and representative sample as it is not statistically analyzing responses (c.f. quantitative research). According to Liamputtong and Serry (2010) purposive sampling in qualitative research seeks participants who are able to provide an in-depth description about the phenomenon being examined.

Five people with ESKD who had been receiving haemodialysis treatment were purposively recruited from two small satellite dialysis units attached to regional hospitals located in rural NSW Australia. Satellite dialysis units are commonly used across Australia in metropolitan, regional and rural settings. These units provide services closer to peoples' homes, and for people living in regional and rural locations, these units avoid people having to re-locate hundreds (or even thousands) of kilometers for renal health care (Agar et al. 2007). Typically a satellite dialysis unit is staffed by registered and enrolled nurses with very limited access to a renal medical physician [nephrologist] who may be present in the renal unit one day per month and with almost no other medical support on-site in the dialysis unit. Medical support may be available elsewhere in the hospital (e.g. emergency department), or a satellite unit may be located in a free-standing place (e.g. converted house) so the only option available in an emergency situation is to call an ambulance. Ideally satellite dialysis units have 'relatively' stable patients. All of the participants in this study lived in nearby regional towns or small rural communities (i.e. villages), where aged between 45-72 years of age, and where

either retired or unable to work. No other demographic information was required for this study.

Data Collection

In-depth semi-structured audio-recorded interviews lasting for 60 minutes were conducted by one of the authors. In some cases participants asked to be interviewed while being dialysed, while other participants were interviewed at other locations of their choice (i.e. in their home). Consistent with qualitative research methods and particularly with exploratory research, interview questions were developed from the information practices literature and focused on understanding the modalities of information used; identifying the information skills people used to understand about kidney disease and its treatment; and the role of health professionals in providing information (see table 1). Collecting data through semi-structured interviews also allowed the researcher to clarify participants' answers and to encourage participants to expand on their responses by using probing questions such 'please tell me more about...' or 'can you explain...for me'.

Table One Interview Guide

- How do you obtain information about your illness?
- What types of information are important?
- Who gives you the most useful information?
- Where do you get information from?
- How does that information help you to understand your illness?
- What would be the best time to give you information about your illness?
- How does that information improve your understanding?
- How important is your nurse in providing information?
- What sources of information do you trust the most?
- Why do you trust this information?

Ethical Considerations

Human Research Ethics Committees for both hospitals and the local university provided ethical approval for the study. Voluntary informed consent was obtained from participants prior to data collection, and data was de-identified.

Data Analysis

Following verbatim transcription, thematic analysis, a method for identifying themes, essences or patterns within interviews (Tuckett 2005, Schneider et al. 2007) was used. The thematic analytical technique described by Liamputtong and Serry (2010) was adapted. It involved each author individually reading, interpreting and manually coding each transcript and then clustering the codes into groups with similar themes (i.e. meaning). In the next phase of analysis, the authors worked together using the groups to develop larger clusters of highly conceptualized groups. Finally through an exhaustive process of analysis and comparison back to the original transcripts, data were clustered into the major themes. These themes were then evaluated for the most appropriate fit with the original data and analytical saturation (i.e. rigor); that is saturation became evident as no new themes emerged.

FINDINGS

Four men and one woman participated in the study and they had been receiving haemodialysis therapy between six months to twenty one years; one participant had, in the past, received peritoneal dialysis and had a kidney transplant. Thematic analysis revealed two types of participants: the first type appears to adopt a received view of information, and the other type, were found to be engaged. Below we explore the features of ‘receivers’ or ‘engagers’ of information.

Receivers

The first type, we have conceptually termed ‘receivers’, appears to adopt a received view of information, and did not question their condition or treatment, nor did they actively seek information. They preferred to be given information from others and passively accepted the information provided. For instance one participant stated that: *“well the information that I got in the beginning I was quite happy with that and I never, I never really gone into it any further than that ... and I'm going to accept that”* (Participant 3). Another participant *“was told in Sydney that I just go straight onto the machine ... [and] I don't think I needed a choice”* (Participant 1).

‘Receivers’ seemed to rely on fewer sources of information, and their primary source was typically the nephrologist who provided verbal information. This appeared to relate to the participants’ unquestioning view of healthcare as being the domain of medical practitioners and because *“[the nephrologist] he gives me my medication, he's the chief giver of – I call him the chief guru he gives you that information, he tells you why you're getting that tablet and he will also say to you now that will react like this”* (Participant 5).

‘Receivers’ identified written information as their main source of information. These sources were books about living with kidney disease, printed notes (often from the dietician) or pamphlets. When ‘receivers’ were provided with any written information they indicated that they collected it but when probed further about this information, they did not seem to use it or even know if it was useful information. For instance participant one stated: *“a drug company they send information on a regular basis...it just came out of the blue ... it was sort of a carry bag incentive type thing and then I started getting these things through the mail and they gave us folders and that to keep everything they sent you to put them in order sort of thing”* (Participant 1). There was also little evidence that ‘receivers’ used the internet or social

media as a source, but this may be the result of the age or educational background of the participants in this study and is an area that requires further exploration.

All participants were specifically asked about the information provided by nursing staff. 'Receivers' trusted nurses as information sources specifically and only ever when it was related to the performance of haemodialysis treatment; they also passively accepted this haemodialysis information. As one participant explained: *"...so you know the [dialysis nurses] like you to be weighed and that determines your fluid level and they say right oh that's such and such and... they work it out ...[and] I don't say anything I just let them do it, you know they're trained and know what it's all about"* (Participant 4).

Engagers

The other type we have conceptually termed 'engagers', and these participants actively identified their information needs and sought out information from a variety of sources. They quickly learned what that they needed to ask, who to ask, were not afraid to ask, and according to one participant *"a lot of people are not interested but I like to know what's going on"* (Participant 2). Another participant, who had been receiving haemodialysis treatment for nearly four years, stated that *"even to this day if I don't understand something and I want to know something, I'll say to [the nephrologist] what is this, why is that, why is the reading rapid and he'll sit down and explain every single detail, even either drawing diagrams or to using things on his desk to show me how it works"* (Participant 5).

Participants who were engaged were able to identify and describe a wide range of information sources that helped inform them of their disease and inform the options available to them. This group was enriched through their level of engagement with information and felt

empowered and engaged in the management of their disease. They also demonstrated a capacity to broaden their information landscape to include distributed sources of information. They identified a number of members of the multi-disciplinary renal health care team (nephrologist, nephrology nurses, vascular surgeon, dietician & pharmacist), kidney foundation and drug companies as providing information. ‘Engagers’ also recognised that other patients were useful information sources saw information sharing as a way not only to obtain information but also to disseminate their embodied knowledge of the disease and treatment to other patients in similar situations. For example participant revealed that *“I get a lot of information from the other clients in the clinic that are in the same boat as I am or worse you know and I get a lot of information off of them because they’re quite willing to tell you their experiences and they have been on it a lot longer than I have and so you pick up a lot of information from them”*.

For participants who actively engaged with information, they were able to describe a variety of formats of information. This included written, audiovisual (e.g. DVD), internet sources (including online CKD chat-rooms), and illustrations. For one participant it *“really was a strength in combining verbal and written information in as much that it was clearly stated and you could just follow and because these others had been so clear in what they told you, you could tie the two together quite easily”* (Participant 5). However, ‘engagers’ also recognised that too much information could be overwhelming for people who were new to the dialysis unit and that *“... the first time you just don’t know what’s going to happen and I’m not real sure if a heap of information is real good, tell them what they ask and what they need to know and you don’t want to scare them”* (Participant 2).

Engaged patients appeared to make judgements about nurses' knowledge and their ability to answer their questions. Long periods of dialysing allowed participants to observe nurses in practice, allowing them to make assessments of nurses embodied knowledge. They actively and deliberately sought advice from these nurses. This participant articulated a common view that, *"nurses are not backward in coming forward and telling you what's wrong and what's not wrong and what you can do to help it you know and they watch you all the time that you're in the [dialysis unit]... so the most important and the most useful information comes from I would say the nurses in the clinic"* (Participant 4). Not surprisingly according to 'engagers', *"you depend a lot more on the nurses than you do the doctors ... cause you see them all the time. You only see the specialist once a month and you only see him for 5 minutes and you're with the nurses 3 days a week for 6 or 7 hours a day so it's got to come from somewhere"* (Participant 5).

DISCUSSION

According to Lloyd (2010, p.11) in order "to understand how knowledge is constructed [of kidney disease and its treatment] it is important to understand how an individual interacts with one of the basic building blocks – information and the process of gathering information". As a framework for researching, information practice helps us to understand how people take on board information and how they develop a way of knowing a specific information landscape (i.e. the information landscape associated with kidney disease). This approach enables us to examine the interplay between information, knowledge and experience. The findings from this exploratory study are, therefore, instructive to our understanding of how people come to live with ESKD and its complex treatment regimen. We found that people are likely to be 'receivers' or 'engagers' with knowledge and experiences at various times in their renal disease journey and this experience is cyclical and

iterative. Being a 'receiver' could be viewed as existing at one end of a continuum with 'engagers' at the other, with people returning to a previous stage as new information is introduced to their lives as their ESKD progresses. 'Receivers' are people who do not interact with information but merely acquire it passively; being passive is their way of coping with kidney disease and receiving haemodialysis. In contrast, 'engagers' actively sought out and interacted with information, and they used information to better understand and cope with kidney disease and its treatment. In addition, the internet as a source of information was not prominent in our findings although there are increasing reliable ESKD information sources available for patients on the internet (Buettner & Fadem 2008). Our findings seem to be consistent with results from a previous study by Orsino et al (2003) who found that older patients tended to be more passive, relied on verbal information, and deferred decision-making to health care professionals and. Our study also contradicts Orsino et al (2003), as we found that haemodialysis patients, regardless of age, can be actively engaged with information.

According to Ormandy (2008) there is sufficient evidence to explain the differences between patients, knowledge levels and information needs. Being able to determine (i.e. assess) the information practices (rather than focusing solely on needs) of renal patients could inform patient education strategies including the appropriate timing, content, and teaching techniques. Knowing whether a person tends to be a 'receiver' or 'engager' with information would enable patient education that focuses on supporting and developing chronic self-care ability to be individually tailored to suit the information practices of people rather than adopting a one-size fits all approach to patient education. This would be useful in all renal settings where patient education is provided including pre-dialysis, conservative care, the dialysis unit and following a kidney transplant. Similarly knowing whether a person tends to

be either a 'receiver' or 'engager' could also alter health care strategies related to increasing adherence with treatment regimens. Indeed educators of patients with chronic kidney disease or other complex chronic conditions would then be satisfied that "information has been understood, assimilated and retained" (Ormandy 2008, p. 26).

Both 'receivers' and 'engagers' reported the central role of nephrology nurses in assisting them to acquire, understand and use information. This is not surprising as haemodialysis patients spend the majority of their time interacting with nurses and they are in position to make individual assessments of nurses' embodied knowledge. According to Bonner and Lloyd (2011) nephrology nurses' embodied knowledge is drawn from several sources and that it is revealed at the moment of practice. 'Receivers' and 'engagers' recognised that nephrology nurses were expert health professionals, particularly with understanding and performing haemodialysis treatment, and that information from nurses could be trusted. Clearly nurses working in the variety of renal patient care areas such as CKD clinics, home training units, dialysis units and transplant wards would find it helpful if they were better able to understand how patients interact with information, and to use this knowledge to improve their ability to support people to adhere to their treatment regimens (e.g. fluid restriction).

Limitations

There are some limitations to this study. First the findings focus on the local context and the particular time in which this study took place, the findings will nevertheless resonate with other people with ESKD and those who provide renal health care. It ought to be remembered that it is the intention of qualitative findings to be transferable rather than to be generalizable (Polit & Tatano Beck 2010). We also employed several strategies used in qualitative research to maximize confirmability, dependability and credibility of the findings (i.e. to minimize the

limitations) including both authors undertaking individual coding of each transcript prior to moving to higher levels of thematic analysis; reflective memoing at the end of each interview which was used to explore our understandings; and a detailed and close immersion in the data occurred during each phase of the analysis.

CONCLUSION

This exploratory study has found that people receiving haemodialysis do have different information practices which seem to exist on a continuum from being a ‘receiver’ to ‘engager’ with information with neither end of the continuum being seen as either problematic or preferable. Rather than focussing on information needs or the lack of knowledge about chronic kidney disease, using the broader perspective of information practices helps to understand the interplay between information and knowledge as it is experienced by people who have renal failure. Knowing the information practices of renal patients, particularly the variety of information sources used is particularly useful for nephrology nurses when planning, implementing and evaluating patient educational strategies. Clearly further research is needed into what it precisely means to be a ‘receiver’ and ‘engager’ of information in people with chronic kidney disease who are at other points of the disease trajectory (e.g. other CKD stages, dialysing at home or in hospitals, following kidney transplantation, etc), and whether people with other complex chronic conditions may also exhibit similar characteristics.

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